

# LEEDS STROKE REVIEW



**Edition 16 – July 2002**

## **Welcome to the latest edition of "Leeds Stroke Review"**

This edition features a review of the **The Stroke Outcome Studies :SOS2&SOS3** by K Hill, A Riach & J Heaton and **Stroke Care Quality in Leeds** by Dr Peter Wanklyn – Consultant Geriatrician .

If you would like to submit an article for the next edition of the Leeds Stroke Review please contact Olasupo Ogunyinka at the address below.

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## **STROKE OUTCOME STUDIES : SOS2 & SOS3**

### **Background**

Last year, the Academic Unit of Psychiatry and Behavioural Sciences at Leeds University successfully bid for funds to conduct two substantial projects. The first of these, from the Stroke Association, is supporting a study of the effect of early depression on outcomes for stroke patients (SOS2) and the second, from the NHS Service Delivery and Organisation (SDO) Research and Development Programme, is funding research into the effects of continuity of care on outcomes after stroke (SOS3).

As the two studies were being planned it became clear that combining the prospective cohort phases of the studies would reduce the burden on patients and allow more time- and cost-effective data collection. Both studies shared the same outcome measures and a joint approach would enable additional follow-up of the study patients at time points when they might have experienced changes in their care or circumstances. Thus it would be possible to obtain a more complete picture of the way in which outcomes may change over time for individual patients. The SOS research portfolio therefore encompasses a series of interlinked projects, each with its own aims and objectives but sharing assessments and data collection where appropriate.

**SOS2:** Depression in the first weeks after stroke: its association with outcomes and its response to antidepressant medication.

Depression has been claimed to have important effects on longer-term outcomes for patients with stroke and particularly on how patients fare in the immediate time after discharge from hospital. This link is perhaps not unexpected as quality of life, most often used to measure this type of outcome, has a large emotional component. However, there are still gaps in our understanding of the effect of depression in stroke patients, especially in the early stages. Evidence to date has been obtained from a number of small studies in which important factors such as the severity of the stroke and the other physical illnesses of the participants have not always been fully considered.

The SOS programme aims to recruit and follow-up 900 patients over 3 years from both the Leeds and Bradford hospitals. Patients will be recruited consecutively after their initial or recurrent episode of stroke and, although some patients will obviously be excluded if they are too poorly or unable to

give consent, we hope to include as many people as possible thereby studying a representative sample. Measures of mood, cognitive function and physical status will be used as the principle outcome measures for the study.

Alongside the question of the effect of depression is the lack of clarity on the real benefits of treatment for depression and its possible disadvantages, particularly in an elderly population. For this reason, a randomized controlled trial of anti-depressant medication will also form part of the main study in order to investigate its effect compared to a placebo (dummy drug) on early depression.

### **SOS3 Continuity of Care in Stroke and its Relation to Outcomes**

**A survey last year by the Stroke Association revealed huge variations in stroke care throughout the country. Notwithstanding the potential bias caused by the poor response rate to this survey it still raises questions about the provision of services for stroke patients in the United Kingdom. As part of the National Service Framework for Older People the Department of Health is committed to improving the quality of services and has emphasised the importance of continuity of care by highlighting it as an area for research.**

SOS 3 will take this research forward in the area of stroke: firstly by developing two simple measures of continuity of care, one using an interview-based study of a group of patients who will be selected to try and cover a range of experience, and the other from a review of their casenotes. Secondly, by applying these measures to the patients in the cohort study already in place for SOS 2, we will assess the effect of continuity of care on outcomes. At the same time SOS 3 will enquire into the meanings of continuity of care for patients and their carers, and will extend this further by seeking the views of the professionals involved in providing stroke care services.

Finally, the study will use the results of the earlier phases to test the feasibility of developing a care package for the first year after stroke. This will specifically address the issue of continuity of care throughout the patient's journey through the health care services.

Stroke is a major disabling disease which causes distress to patients and often places a burden of care on their families. This research will help inform service providers about which aspects of care patients and their carers value most thus enabling them to build a better, more patient-centred service for the future.

If you would like further information about either of the studies described here please contact one of the project staff :

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### **WHAT IS BEING DONE TO MEASURE STROKE CARE QUALITY IN LEEDS?**

Measuring the quality of stroke care may, on the surface, sound straightforward. One definition of the quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes. Quality of care could be broken down to structure of care, process of care and outcome of care. Structure includes the facilities, equipment and services which are available. An example would be the availability of trained multidisciplinary staff. The process of care refers to the operational characteristics of available services. An example of this would be rapid access to CT scanning in acute stroke or use of a Care Pathway. Finally, the outcome of care refers to the effect on the individual and examples might include death, disability or institutionalisation. This definition of quality of care is a little narrow in the sense that it does not recognise the importance of patient and carer feedback, which is another component of the picture.

#### **1. Outcome measures**

These can often be easy to identify and appear to have face validity. However, they are often misleading as measures of a service in that they depend intrinsically on accurate diagnosis and case mix. For example, hospitals with units which take a disproportionately large number of older patients will have worse mortality figures for stroke. In addition, non-stroke co-morbid conditions and social circumstances have a crucial effect on many commonly used outcome measures. Finally, outcomes will vary over a period of time and often studies have

been done over too short a period and with too few patients to properly show any real significant differences between units or services.

## **2. Process measures**

These should be based on up-to-date evidence base indicating a link between an intervention and a positive beneficial affect, i.e. it is crucial that a strong link can be demonstrated between the process of care and outcome measure. The process of care measure may then be used as a proxy for outcome in practice.

## **3. Structure of care**

Proven links between structures and outcomes of care are few and far between. The presence or absence of a stroke unit would be one example but only if the stroke unit had the general characteristics identified by the Stroke Unit Trialists in terms of organisation and processes.

In summary, outcome measures may be affected by many other factors besides the structure or process of care that exists locally and this largely relates to patient case mix. At the present time it is very difficult to adjust for case mix in stroke care and, therefore, it has been suggested that we concentrate for the moment on assessing process and structure measures. I also believe that a modern service should gather patient and carer feedback using any valid measures which are available. I would like to outline what measures we currently use in Leeds and would encourage people to provide feedback and suggestions on any other actions that can be taken.

## **Outcomes**

The Leeds Stroke Database has been operational for eight years now and routinely gathers follow up data at 6 months. This includes mortality, disability and institutionalisation rates. The audit data is aggregated and 6 monthly reports are produced. In view of the fact that the outcome measures are highly case mix dependent, the results are not widely circulated at the current time.

## **Process of care measures**

A number of local audits have taken place across Leeds examining particular areas of care, for instance, carotid duplex imaging, medication for particular indications, acute care interventions etc. However, the most

comprehensive review of care processes has taken place during the National Sentinel Audit of Stroke. This audit uses comprehensive standards outlined in the Inter-collegiate National Clinical Guidelines. These are available on [www.rcplondon.ac.uk/pubs/books/stroke/index](http://www.rcplondon.ac.uk/pubs/books/stroke/index). The first 2 cycles of the audit took place in 1998 and 1999 and showed there were very significant areas of stroke care that needed improvement. There were major changes evident between those first 2 audits and improvements in both hospital and primary care services.

Many DGH's set up specialist stroke services at around that time. The latest audit took place in 2001/2 and the results were available in May. Over 95% of acute trusts in England, Wales and Northern Ireland took part in the audit which is the largest ever audit of stroke care. Overall some of the key findings of the resultant report are that 173 (73%) of the participating sites now have a stroke unit. However, only 36% of admitted patients spend any time on a stroke unit. Eight percent of trusts now have a clinician with responsibility for stroke but the average amount of time spent by this lead clinician in stroke care was a median of only two sessions. This is clearly inadequate and there needs to be an expansion in specialist stroke physicians. Some of the other highlights from the report are that only 64% of patients are having a swallowing assessment, 63% have visual fields recorded and only 49% were weighed at least once during the admission. However, on a more positive note, more patients than ever are having brain imaging with at least 83% documented and 91% of patients were on appropriate anti-thrombotic medication at discharge and 6 month follow up.

Stroke services within the City are developed to a greater extent in Leeds West than in Leeds East and for this reason we decided to divide the City in two so that we now have two separate audit reports, one for Leeds East and one for Leeds West. The audit itself is also divided into two parts. Firstly, there is an organisational audit which examines mainly structures, for instance, whether there is a proper stroke unit and how many beds it has, staffing levels, presence of in-house continuing education in stroke, use of care pathways and multidisciplinary records, use of team meetings, agreed assessment measures and communication issues. The score range from 0-100 with 100 being perfect. The second part of the audit was a retrospective case note review of 40 consecutive stroke patients admitted from 1 April 2001. A large number of parameters were used, split into 8 sections. These sections included initial patient assessment, clinical diagnosis, multidisciplinary assessment, screening and functional

assessment, management/care planning, communication with patients and carers, primary/secondary care interface and 6 month follow up and review. Once again, the scores range from 0-100 with 100 being perfect. The scores achieved on each side of the City are given below with the comparison with mean for all trusts included across the country.

The large difference in organisation of services is not surprising given the failure to organise and invest in adequately resourced stroke units in Leeds East. A business case has gone forward from the Acute Trust to the Commissioners for the last 2 years running to develop a fully funded

stroke rehabilitation unit and an acute stroke unit but they have both been rejected. The process of care audit showed that in Leeds West 78% of patients were treated on a stroke unit at any time during their stay with a median delay to admission to the stroke unit of 2 days. The equivalent figures for Leeds East were that 31% were treated on a stroke unit at any time during their stay with a median delay of 20 days. The overall scores for the clinical audit also indicated a large difference in the process of care between Leeds East and Leeds West which can only be addressed by a properly resourced service. This will be taken forward once again to the Commissioners as part of the work of the NSF Task Group.

### National Stroke Audit results

Year		Leeds East	Leeds West	Median for all Trusts (n=199, 95% of total)
1999	Organisation of services	65	74	Not applicable
	Clinical process of care audit (n=40, for west, 39 for east)	53	58	62
<b>2001</b>	<b>Organisation of services</b>	<b>18</b>	<b>64</b>	<b>62</b>

	<b>Clinical process of care audit (n=40, for west, 39 for east)</b>	<b>60</b>	<b>73</b>	<b>60</b>
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### **Patient and carer feedback**

We have previously conducted a feedback questionnaire from patients and carers 2 years ago in Leeds West, which showed generally high levels of satisfaction with all aspects of care from nursing to therapy to information provision. However, there were some individual pieces of negative feedback that led to changes in the service. This particularly included a few patients who did not feel their information needs had been delivered and also some comments about night-time care. We intend to extend this feedback gathering as part of the Leeds Stroke Database activity of gaining follow up information at 6 months. Rather than designing our own questionnaire, examination of the literature revealed that a feedback questionnaire has been validated (Pound P, Gompertz P, Ebrahim S. Clinical Rehabilitation 1994;8: 7-17). This includes components of satisfaction with both hospital care and on post discharge care in the community. We will shortly begin including this questionnaire to between 50 and 100 patients every 6 months. This will then form a component of the Leeds Stroke Database report.

**Dr Peter Wanklyn  
June 2002**

### **Net News**

There has been few changes to Leeds Stroke Database web site as follows:

- Stroke Research in Leeds
- The Multidisciplinary Integrated Stroke Care Pathway designed for use in the Leeds Teaching Hospitals NHS Trust and The Leeds Stroke Clerking Proforma which has been adapted for local use from the original Stroke Clerking proforma designed by the Royal College of Physicians, London can now be downloaded in pdf file under PROFESSIONALS page.

Our site was submitted for Bobby approval and has been approved. Please do visit our web site : [www.leedsstrokedatabase.net](http://www.leedsstrokedatabase.net) and let us know if

there is anything we have missed or you want us to provide information on. Email to:  
[olasupo.ogunyinka@leedsth.nhs.uk](mailto:olasupo.ogunyinka@leedsth.nhs.uk)

### **CERTIFICATE IN STROKE CARE**

Recruitment for the Certificate in Stroke Care (University of Leeds) is now underway. If you would like further information about this 60 credit multidisciplinary course please contact:

**Anne Foster** [a.forster@leeds.ac.uk](mailto:a.forster@leeds.ac.uk) 01274 365311 or 0113 343 5654 or

**Carol Twomey** 0113 343 1360 [c.a.m.twomey@leeds.ac.uk](mailto:c.a.m.twomey@leeds.ac.uk)

### **Improving Stroke Services in Leeds – an update.**

Work is underway to improve the effectiveness of stroke services in Leeds. A lot has happened since the last Leeds Stroke Review in January 2002.

The stroke steering group established following the workshop at South Leeds stadium in October 2001 has set up 6 sub-groups looking at all aspects of stroke from prevention, diagnosis, acute hospital care, discharge planning, rehabilitation and long term support.

A Stroke Project Manager started in February 2002 based with the older peoples' team at Leeds West PCT. She is liaising with the 6 subgroups and steering group producing a process map of current services for stroke, informed by staff and patient interviews, audits and the Leeds Stroke Database.

Linking with the work of the other Standards of the Older Peoples' NSF.

Liaising with a wide range of stakeholders including LTHT, PCTs, social services, voluntary sector organisations and service users.

Working in conjunction with the Leeds Stroke Database to expand the list of useful information and organisations available on their website.

### **How can I help?**



This is your opportunity to let us know how best to improve stroke services for you & your patients. Go on – don't keep it to yourself. If you have any ideas on how things can be improved please contact:

Debbie Neal, (Stroke care pathways project manager)~: 0113 3059449

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